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ABSTRACT

This document is a progress report on a British project designed to help disabled adults gain self-advocacy skills, becoming active consumers of the rights and benefits to which they are entitled. The aims of the project, which began in September 1988, are as follows: (1) promote staff development on advocacy among professionals working with the disabled; (2) research how unemployed disabled adults might maximize their potential by developing self-advocacy skills, transferring such skills to new situations, and developing a personal portfolio; and (3) assess the process of portfolio preparation as a tool and the use of portfolios as a finished product. Eleven case studies are being prepared, involving more than 30 learners and 13 key workers chosen to provide wide examples of physical and intellectual impairments, a range of agencies and professional backgrounds, ethnic diversity, and a variety of ages. Issues that have been raised concern the following areas: (1) principle and direction; (2) interagency cooperation; (3) necessary personal and professional skills for key workers; (4) the ethos of institutions; (5) implementation of self-advocacy work by key workers; and (6) the position of learners. (CML)

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This right to self-advocacy was recognised by the Further Education Unit (FEU) as long ago as 1986. The work of REPLAN over the last few years has also highlighted the role adult education can play in restoring self-worth and opening doors for unemployed adults. Additionally, the self-advocacy movements such as 'People First' and voluntary organisations like SKILL (National Bureau for Students with Disabilities) have developed significant work in this area. It is now a matter of urgency that professionals reappraise their own position with regard to the self-advocacy needs of all disabled adults. This bulletin is a progress report on the work of the FEU REPLAN project 'Working with Disabled Unemployed Adults to Develop Self-Advocacy Skills' (RP449), an important exploration of staff development needs in this field. The project is closely associated with the key transitional experiences explored in the FEU project (RP510) in connection with the OECD/CERI Disabled Action Programme. (The first of three bulletins describing the work of this project, Transition to Adult Life, *was published in May 1989.)*

Background

In 1986, the East Midlands Further Education Council (EMFEC) REPLAN Special Needs Group identified the development of self-advocacy skills as a priority for its work with disabled, unemployed adults. The FEU publication *Transition to Adulthood* (1986) and the OECD's *Handicapped Adolescent* had already emphasised the lack of opportunities for disabled adults and the confusion of benefits and agencies that are supposed to assist them. If the rights of all individuals to the 'significant' lives advocated by the Warnock Report were to be fulfilled, disabled people clearly needed to be able to speak for themselves. To these considerations was added the need for disabled people to be proactive if they were to become the active consumers assumed within the Disabled Persons Act, 1986.

Other work had already been undertaken in the area, notably *Adult Unemployment and the Curriculum* (FEU, 1985) and 'Skills Assessment and Vocational Guidance for Unemployed People' (RP321) (to be published during 1989). The FEU REPLAN project RP449 was set up to

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Self-Advocacy Skills for People with Disabilities

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draw together the threads of this previous work as they relate to adults with disabilities.

Aims

The project aims to:

- promote staff development in the field of self-advocacy for professionals working with unemployed adults with special needs;
- research how unemployed, disabled adults might maximise their potential by making the most effective use of available opportunities through:
  - the development of self-advocacy skills;
  - transferring such skills to new situations;
  - developing a personal portfolio;
- assess the process of portfolio preparation as a tool in the acquisition of self-advocacy skills, and evaluate the use of portfolios as a finished product.

Organisation

A Project Officer was appointed and a timetable for meeting the project's objectives established. Support was provided by FEU, EMFEC's Special Needs Advisory Group and a Project Consultant. A case-study approach was decided upon and the research methods determined. These included:

- questionnaires;
- extended supervision of key workers;
- development activities for key workers;
- extended interviews;
- structured logs and diaries;
- use of consultant;
- some participant observation.

A Steering Committee was established with representation from FEU, HMI, special needs interests within further education, SKILL, MENCAP, the consumer-led Derbyshire Cente for Integrated Living, Nottingham Advocacy Alliance and Lincolnshire Social Services.

Getting started: September 1988

A review of developments in the field of self-advocacy was undertaken and a definitions paper was prepared for the Steering Committee.

Eleven case studies were identified. These involve over 30 learners and 13 key workers chosen to cover:

- a wide spread of impairment, both physical and intellectual;
- a range of agencies and professional backgrounds;
- ethnic diversity;
- a variety of ages.

The learners include, for example, a profoundly and multiply disabled young man resident in a long-stay hospital; a young woman with moderate learning difficulties working with The Rathbone Society and living at home; an older man, newly relocated in the community after many years in a psychiatric hospital; a highly able young Asian with a degenerative muscle disorder at an FE unit for students unable to attend a mainstream college.

The key workers were already aware of the issues involved in self-advocacy. The group includes FE lecturers, both within and outside formal college settings, a social worker, a day care officer, an occupational therapist and a nurse turned community worker. They all have management support for the time they need to be released for the project work, but the overall orientation of their working backgrounds varies considerably.

Staff development for key workers: October 1988 to February 1989

Among the major aims of the development work with the key workers were:

- the creation of a project identity;
- the establishment of mutual support by the key workers;

- the establishment of an agreed framework for research;
- an identification of the principles of portfolio preparation, assisted by an expert in the field;
- the reapplication of these principles to unemployed adults with special needs;
- the support of the key workers in using the experiential learning cycle (Kolb's Experiential Learning Cycle, see *Learning By Doing* FEU, 1988) with confidence in monitoring and reporting their work.

Implementation

The Project Officer was responsible for directing, supporting, monitoring and evaluating the action research undertaken by the key workers. An interim report was presented to the project steering group in November 1988. Certain key issues have already arisen from the project's activities.

Issues arising from the work to date

Fundamental issues of principle and direction

- Is it ethical to raise learners' expectations when these may not be able to be met because of lack of resources or well-planned provision, or hostility from other service-providers?
- Where does the accountability of professionals lie when they consider themselves allies of self-advocating learners? Conflicts within organisations or between different professionals can arise over risk-taking or the sharing of confidential information.
- In what ways it is possible for professionals to demystify their specialist knowledge and skills and make them available to learners on a more egalitarian basis?
- To what extent are professionals still involved in judging individuals, investing them with labels and acting as a brake on the potential for self-advocacy amongst people with disabilities?

Issues arising from interagency co-operation

These include:

- Differences in the scope of various professionals' roles.
- The use of portfolios for different purposes in different service settings.
- The value of cross-disciplinary exchanges.
- The difficulties caused by conflicting definitions of disability used by different agencies.
- The problems caused by differential conditions of service and pay between groups of professionals.

Issues about the necessary personal and professional skills for key workers

Key competences for workers would be:

- The capacity to define personal boundaries.
- Interpersonal competences.
- The capacity to share skills.
- The capacity to take advantage of personal supervision and reflective discussion with an objective colleague.
- The capacity to organise *real* choices for people with disabilities.

Issues about the ethos of institutions

- Is there an acceptance that people with disabilities have the right to a normal life?
- Does the 'medical model' dominate?
- Are there clearly laid down rights for service-users?
- Are there grievance procedures for service-users?
- What resources exist and how are they allocated?
- Does the institution manage and support change effectively for its staff and clients?

Issues about the implementation of self-advocacy work by key workers

- What is the status of staff who initiate self-advocacy work?

- **What tension exists between staff from different disciplines?**
- **What conflicts of loyalty/professional accountability exist and how are they resolved?**

Issues about the position of learners

- **Does the environment encourage autonomy?**
- **Are real choices available?**
- **How damaged is the learner's sense of self-worth?**

Outcomes

The project will be completed in September 1989. The final report will describe the practice of the case studies, analyse the issues and make recommendations. It will focus on the role of education in promoting self-advocacy skills and the effectiveness of portfolio preparation in this process and will seek to lay down guidelines for professionals in education and other services who are developing self-advocacy skills with learners.

The project will be part of the national dissemination of the UK contribution (RP510) to the OECD/CERI Disabled Action Programme in late 1989.

Further information

For further information about this project, please contact Christine Moore (Project Director) or Mariette Clare (Project Worker) at East Midlands Further Education Council, Robins Wood House, Robins Wood Road, Aspley, Nottingham NG8 3NH (tel: 0602 293291) or Patricia Hood, Development Officer, FEU, 2 Orange Street, London WC2H 7WE (tel: 01–321 0433).

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